

An Overview of the World Trade Center Health Registry

Sixth Meeting of the WTC Expert Technical Review Panel
St. John's University
September 13, 2004

What is a Health Registry?

- A Health Registry is a listing of persons with common exposures
- A Registry collects health information about participants over time in order to detect potential adverse health effects
- Potential adverse health effects detected by Registries are used to generate hypotheses and to design in depth follow-up studies
- Information gained from a Health Registry can be generalized to other exposed groups who are not eligible for enrollment

A Health Registry: What it is not

- A Health Registry is not a study
- It is not a medical screening program
- A Registry is not a probability sample of exposed persons or populations
- Registries do not have control groups

Background

- Hundreds of thousands of people were exposed to the immense cloud of dust and debris, the indoor dust, the fumes from persistent fires, and the trauma of the terrorist attacks on the World Trade Centers
- The WTC Health Registry was conceived as an imperative public health response to document and evaluate the impact of the disaster on large and diverse populations
- The WTCHR is a collaborative scientific effort by DOHMH, ATSDR, and external scientific and community partners
- Funding has been provided by FEMA, ATSDR, and the NYC DOHMH

Goal

- To evaluate the short- and long-term physical and mental health effects that may have resulted from exposure to the 9/11 disaster

Objectives

- To detect physical and mental health effects across a wide range of exposures
- To investigate potential health effects identified by the Registry with more in depth follow-up studies
- To provide a means for very long term follow-up (at least 20 years) of a large group of exposed persons
- To provide data that may assist in the development of screening and intervention programs

Methods

- Identify highly exposed persons through lists of employees in damaged and destroyed buildings and area residents
- Conduct extensive outreach to encourage enrollment by persons not on lists
- Baseline survey collects demographics, exposure measures, self-reported physical symptoms and conditions, mental health screening, and information for future contact
- Survey data collected by Computer Assisted Telephone/Personal Interview

Community Outreach

- Initiated a Community Advisory Board that meets quarterly
- Contacted management offices in 148 largest residential buildings south of Chambers: provided door-to-door interviews, information tables, and door-to door brochures
- Met with parent coordinators at 13 public schools and daycare and private schools; presentations have been given at PTA and staff meetings, “backpack” letters sent with students and mailings to parents
- Placed brochure stands at > 1,000 businesses in lower Manhattan, refill these at least every 2-3 weeks

Enrollment Criteria

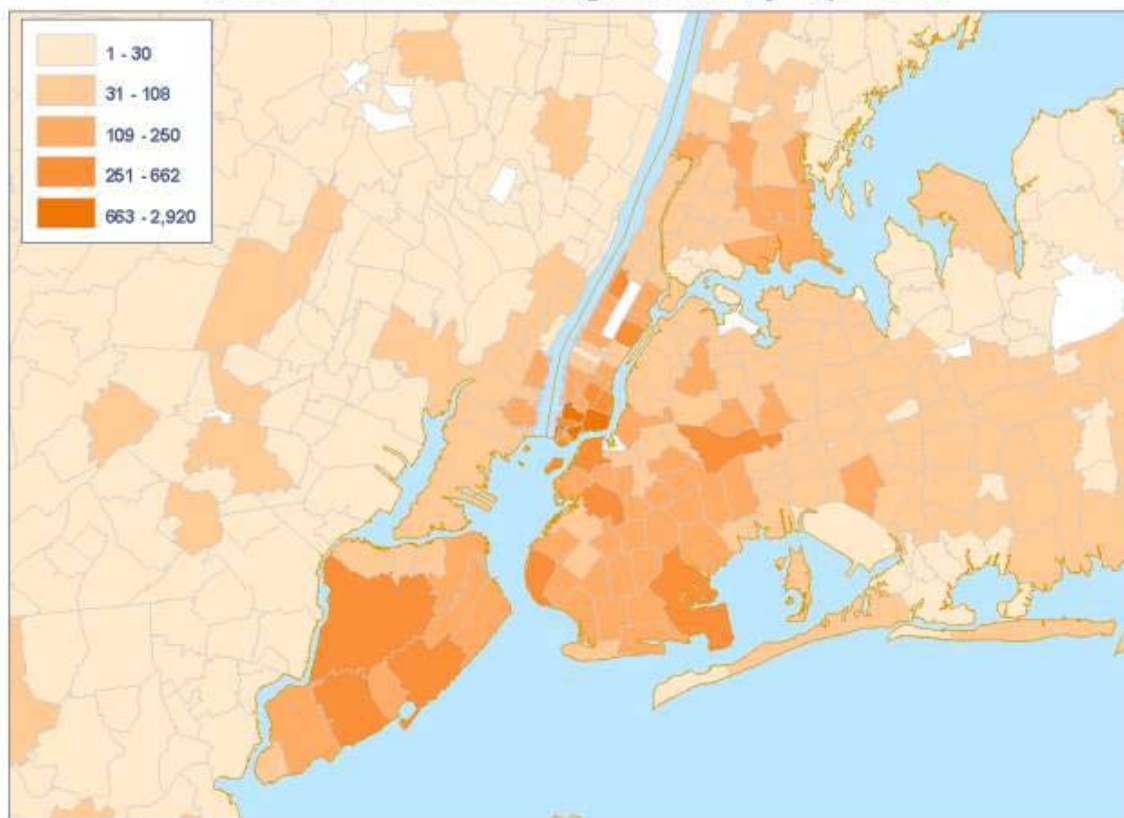
- People south of Chambers St. on 9/11
- Primary residence on 9/11 south of Canal St.
- School children and staff enrolled in schools (pre K – 12) south of Canal St. on 9/11
- People involved in efforts at the WTC site and/or WTC recovery operations on S.I. or barges (9/11/01 – 6/30/02)

Eligibility criteria

- Criteria were based on the desire to enroll highly exposed groups with the understanding that our ability to detect an adverse health effect (s), particularly an uncommon effect, would be greatest among these groups
- Boundaries and group definitions were based on the best available information about important exposures
- Needed boundaries and definitions that could be understood by the most people
- Knowledge that not ALL persons exposed would be enrolled

Metropolitan New York/New Jersey Enrollment by Zip Code

World Trade Center Registrants by Zip Code



Enrollment to Date – as of Sept 8, 2004

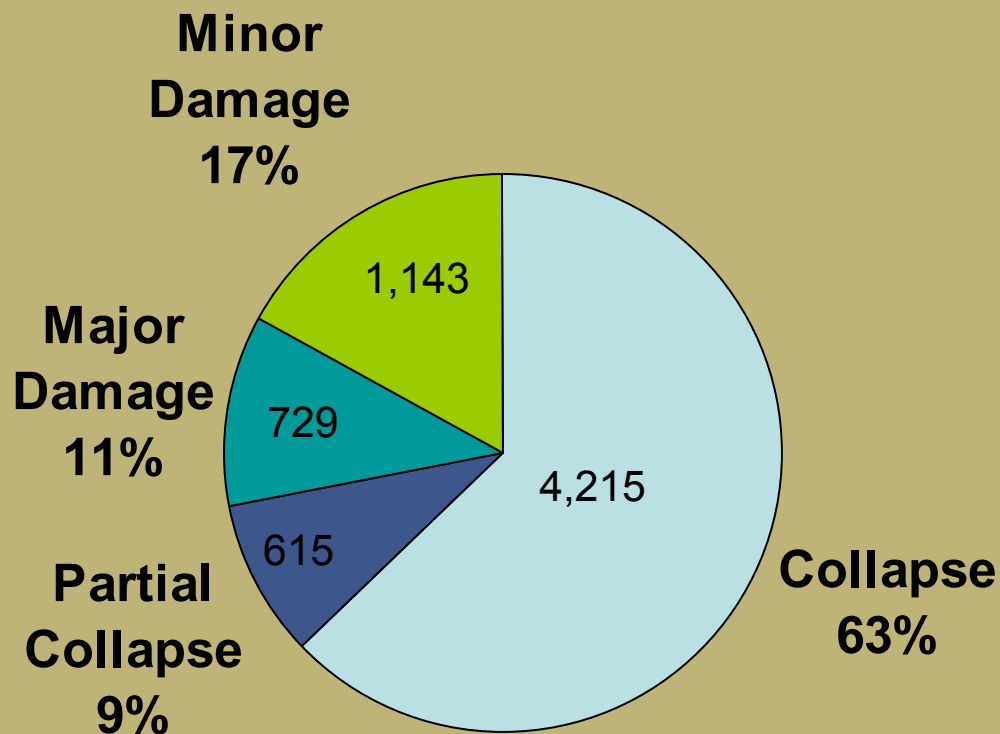
- Total enrolled: **60,740**
- Total rescue/recovery/cleanup workers enrolled: **21,217**
- Total number of residents south of Canal enrolled: **11,726**
- Total students/staff in schools: **1,633**
- Total persons in a building, on the street, or in transit south of Canal on 9/11 enrolled: **26,164**

Source: WTC Executive Summary Report

Enrollment among core exposure groups – as of Sept 8, 2004

Core Exposure groups	Estimated size of eligible population	Number enrolled
Occupants of 35 destroyed and damaged buildings	35,000	7,107 (20%)
Residents who live South of Chambers on 9/11	28,000	7,777 (28%)
School children	14,000	1,633 (12%)
Rescue, recovery, and clean-up workers	40,000	21,217 (53%)
Total	117,000	37,734 (32%)

Enrollees in Damaged and Destroyed Buildings (as of August 28, 2004)



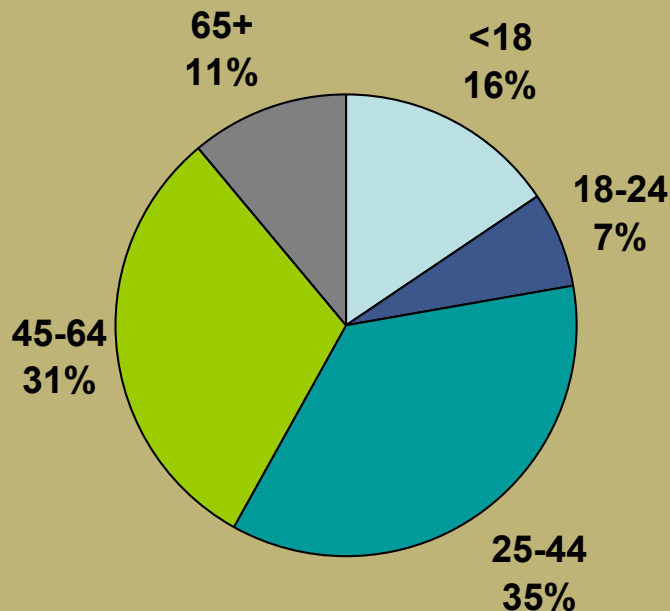
Total: 6,702

Enrollment of Residents in Lower Manhattan (as of August 28, 2004)

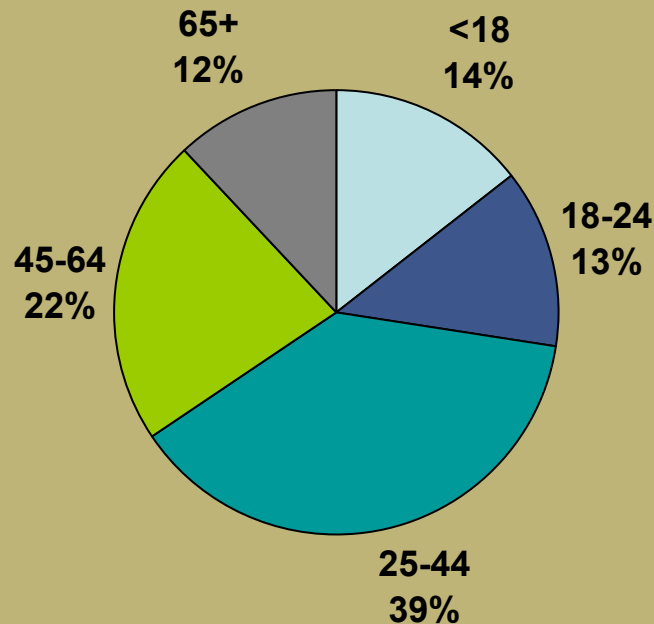
	Number in WTCHR	Population from Census 2000	% Enrolled
Zip Code			
10002	1,926	12,116	16%
10004	383	1,223	31%
10005	137	884	15%
10006	437	1,447	30%
10007	774	4,236	18%
10013	2,545	14,977	17%
10038	3,468	15,574	22%
10280	1,790	6,614	27%
Total	11,460	57,071	20%

Comparison of resident enrollees to US census by age group

WTCHR
Total=11,460

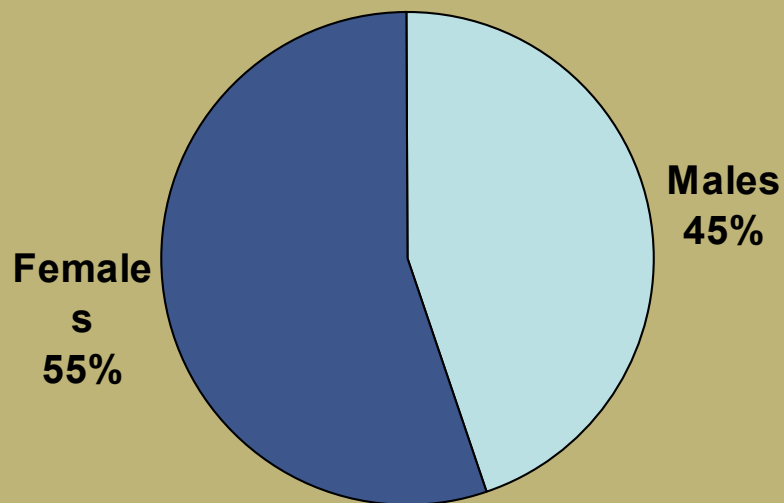


US CENSUS
Total=57511

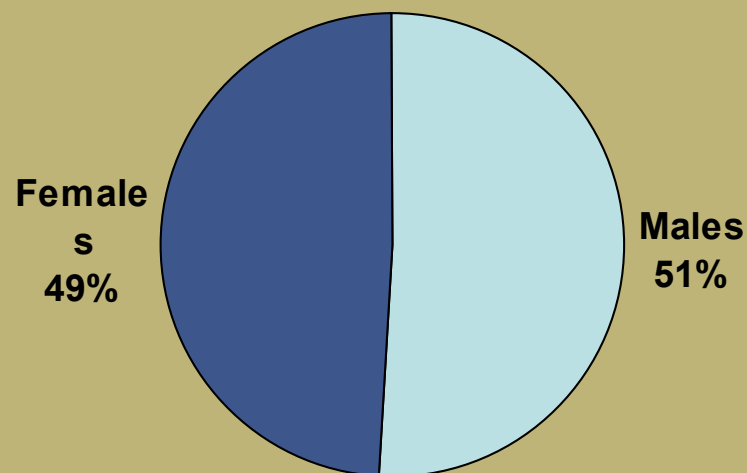


Comparison of resident enrollees to US census by gender

WTCHR
Total=11,460

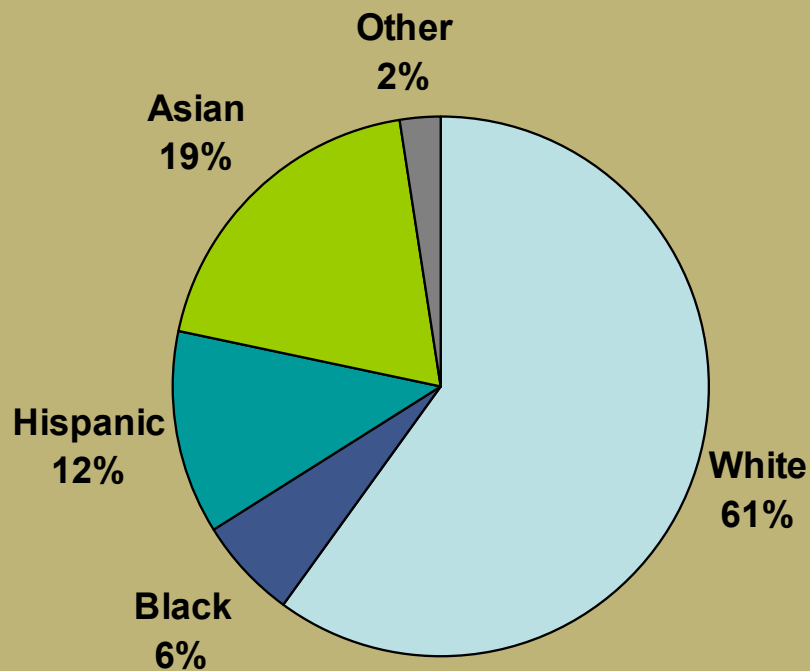


US CENSUS
Total=57511

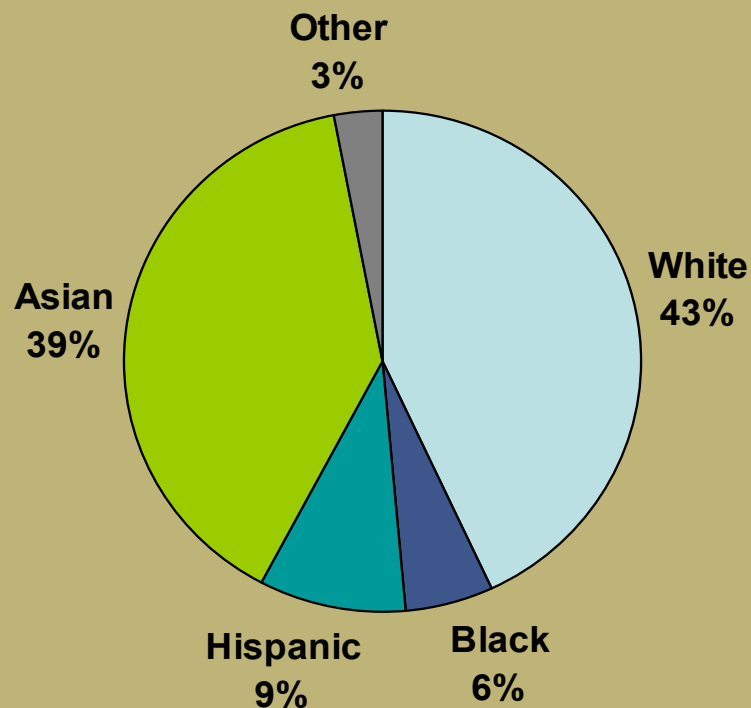


Comparison of resident enrollees to US census by race/ethnicity

WTCHR
Total=11,460



US CENSUS
Total=57511



Enrollment Highlights

- Almost 5000 persons who were in partially or fully collapsed buildings on 9/11 are enrolled in the Registry -- at least 3 times more than other programs focusing on building occupants
- Almost 3000 members of NYPD (~ 60% of the estimated 5000 who worked at the WTC site) have enrolled in the Registry
- More than 1500 sanitation department workers (> 50% of the estimated 3000 who worked at the WTC site) have enrolled in the Registry

Enrollment Needs

- Children
- Some residents groups
- Some worker groups

Limitations or Concerns

- Enrollment began two years after 9/11 (people have moved away; people have died; and people forget)
- Survey does not ask every exposure and health question of interest
- Some groups have fewer enrollees than desired

Strategies to overcome delay in start up

- Used lists of potentially exposed persons to search for current addresses and perform outreach
- Launched an intensive media awareness campaign and conducted extensive outreach
- Interviewed next of kin of people who died since 9/11
- Designed questions to help people remember

Limited number of questions

- Initial questionnaire is designed to gather baseline information on all enrollees in a short period (< 30 minute interview)
- Follow-up surveys will ask supplemental questions tailored to particular exposure groups

Enrollment Expectations

- Enrollment far exceeds expectations based on similar registries
- Registrants can be categorized from very high exposure to environmental agents to minimal exposure and dose response can be assessed
- Although the Registry has lower numbers of some groups than desired (eg, school children), the absolute number of enrollees in most groups exceeds any other currently available data

Methods – Follow-up analysis

- Re-contact registrants every one to two years to update contact and basic health information
- Link registry to cancer, death and hospitalization registries
- Conduct in depth follow-up studies in selected population

Status of continuing interviewing after 8/31

- We are still pursuing registering those groups that were highly exposed and whom we've already identified from outreach and direct contact (next 8 weeks)
- While we are no longer actively promoting the Registry to the general public, any eligible person who still wants to enroll will not be turned away